RESEARCH PAPER

The Public Endorses Collection of Ethnicity Information in Hospital: Implications for Routine Data Capture in Canadian Health Systems

Le public approuve la collecte de renseignements sur l'origine ethnique dans les hôpitaux : répercussions sur la saisie systématique de données dans les systèmes de soins de santé canadiens

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Abstract

A telephone survey was conducted in Calgary, Alberta to assess public opinion on collection of ethnicity information in hospitals. Of the 2,799 respondents, 84.8% felt comfortable about recording their ethnicity in hospital charts. This rate held across respondents' age, marital status and ethnic origin. These findings suggest that Canadian health systems should explore the feasibility and ethical suitability of collecting ethnicity data, as this information could contribute to the evaluation and subsequent reduction of ethnic disparities in health and health services access.

Résumé

Un sondage par téléphone a été mené à Calgary, en Alberta, afin d'évaluer l'opinion publique relativement à la collecte de renseignements sur l'origine ethnique dans les hôpitaux. Des 2 799 répondants, 84,8 p. cent ont dit ne pas avoir d'objection à ce que leur origine ethnique soit inscrite dans leur dossier de patient. Ce pourcentage s'est maintenu chez tous les répondants, quel que soit leur âge, leur état civil et leur origine ethnique. Ces résultats suggèrent que les responsables des systèmes de santé canadiens devraient explorer la faisabilité et le bien-fondé éthique de la collecte de renseignements sur l'origine ethnique, puisque de tels renseignements pourraient aider à évaluer et, subséquemment, à réduire les disparités ethniques dans l'accès aux soins et aux services de santé.

About four million Canadians consider themselves visible minorities, and ethnic minority populations continue to grow in numbers due to immigration (Statistics Canada 2004a). Because of this continuing growth, understanding and reducing health disparities and promoting equality for ethnic minority populations have become top priorities in Canadian research and public policy (Canadian Institute of Health Research 2004). However, ethnic variation in population health, health services utilization and outcomes is little studied in Canada, largely because hospital charts and most routinely compiled health databases do not record information on ethnicity. We conducted a random survey of residents in a large Canadian city to assess how the general public feels about the routine collection and compilation of individual-level data on ethnicity in hospital records.

Methods

Data for this study were collected through a cross-sectional telephone survey using a structured questionnaire in the city of Calgary, Alberta between September and

December 2003. We randomly selected only primary phone numbers from the 2003 Calgary telephone directory for the survey. Information on the type of telephone number – whether it is a primary or secondary residential number – is flagged in the directory. We interviewed one respondent, aged 18 or over, at each telephone number in either English, two major Chinese dialects (Mandarin and Cantonese) or four South Asian dialects (Hindi, Urdu, Punjabi and Gujarati). These languages were chosen because Chinese and South Asian Canadians are the two largest visible minority populations in Calgary (Statistics Canada 2004a).

Our survey questionnaire was developed in English. Forward and backward translations were performed to ensure that the meanings in the translated versions were consistent. A different translator performed each translation. The survey collected data on age, sex, marital status, birthplace, ethnicity and respondents' opinions regarding the routine collection (in hospital records) of information on ethnicity. Self-perception of ancestry of origin was determined by the following question: "People living in Canada come from many different cultural and racial backgrounds. Would you describe your ethnic origins as …" Following the question, various ethnicities were listed for selection. We also asked respondents to describe their ethnicity in their own words. The respondent's opinion on providing ethnicity information to hospitals was collected by asking: "If you were admitted to a hospital, would you feel comfortable having your ethnic or cultural background recorded in hospital charts?" Respondents were given a choice of "Yes," "No" or "Don't Know." Simple descriptive and chi-square statistics were used to describe our findings.

Results

Of 6,585 telephone numbers dialled, 5,124 people were contacted and 3,021 were surveyed, among whom 2,799 had complete data amenable to analysis (55% of the 5,124 individuals contacted). Among these 2,799 respondents with complete data, 84.8% (95% confidence interval: 83.4% to 86.1%) felt comfortable recording their ethnicity in hospital records. This proportion did not vary by age, marital status or race/ethnicity (Table 1). Persons born in Canada (86.2%) were more supportive than immigrants (80.3%).

Discussion

Our study demonstrates that a majority of Calgarians support the collection of ethnicity information in hospital records. This finding suggests that the collection of data on ethnicity in health system databases should be further explored, given the clear importance of this personal variable as a determinant of health and healthcare delivery.

Our study did find that about 15% of respondents reject the concept of recording ethnicity in medical records. Indeed, it must be acknowledged that some consider ethnicity a sensitive and private matter, and when that is the perception among some

TABLE 1. Number (%) of people who felt comfortable recording their ethnicity in hospital charts (Sample size = 2,799)

CHARACTERISTICS	*n* (%)	*p*-VALUE*
Total	2,373 (84.8%)**	
Age		
18 to 34	841 (86.2%)	0.283
35 to 64	1,276 (83.8%)	
65 or over	256 (85.1%)	
Sex		
Male	876 (83.0%)	0.036
Female	1,497 (85.9%)	
Marital Status		
Married	1,262 (84.5%)	0.909
Common-law	165 (84.6%)	
Separated	79 (82.3%)	
Divorced	189 (87.1%)	
Widowed	123 (84.3%)	
Never married	555 (85.1%)	
Birthplace		
Canada	1,818 (86.2%)	<0.001
Other countries	555 (80.3%)	
Ethnicity		
White	2,048 (85.3%)	0.207
Asian	262 (80.9%)	
Chinese	126 (81.3%)	
South-Asian	80 (74.8%)	
Arab/West Asian	29 (93.6%)	
Other Asians	28 (87.5%)	
Aboriginal	23 (88.5%)	
Others	40 (85.1%)	

**p*-values are for the comparison of responses among the subgroups presented.
**95% confidence interval 83.4–86.1%.

individuals, a case could be made against the widespread collection of such information. In Canada, however, the collection of private or sensitive information is not new. Statistics Canada started to collect ethnicity information as early as its first national census in 1871 (Statistics Canada 2005). Two recent national health surveys – the National Population Health Survey (Statistics Canada 2004b) and the Canadian Community Health Survey (Statistics Canada 2003) – also collect ethnicity data. Furthermore, hospital charts and their accompanying administrative databases routinely record patient names and, in some instances, religion, which some would argue is at least as sensitive and personal as ethnicity.

To overcome the lack of ethnicity information in many databases, researchers have recently proposed the use of patient surnames as a proxy for defining ethnicity (Quan et al. 2004; Lauderdale and Kestenbaum 2000). Paradoxically, however, this amounts to using names, arguably the *most* sensitive personal variable in health databases, as a proxy for the perhaps less sensitive variable of ethnicity. Indeed, we anticipate that many individuals would object to having their names used to define ethnicity because a truly personal variable is being used, and also because of the potential for misclassifying ethnicity (e.g., as could occur with the existing name-ethnicity algorithms when a person's last name is "Lee").

A case can indeed be made for the merit of collecting individual-level information on ethnicity in health records and accompanying health system databases. Such information would facilitate research into the health of ethnic minority populations and their access to health services. Health systems in the United States have routinely collected information on race in health records and administrative data, and this information has permitted the compilation of a considerable body of knowledge on racial disparities in health and health system access (Long et al. 2004). Such a body of knowledge provides a foundation for interventions to reduce disparities. Canada, meanwhile, has maintained a commitment to focusing on ethnicity rather than race, as ethnicity more comprehensively represents the cultural factors (beyond skin colour) that are passed through families from generation to generation and that may influence health and health services access and quality.

The validity of ethnicity information has been questioned because of ambiguity surrounding the definition and meaning of ethnicity to patients. The concept of ethnicity is complex. Definitions are multidimensional and may include language, culture, physical appearance, religion, nationality, self-perception and ancestors' place(s) of origin. In our survey, when we asked respondents to describe their ethnicity in their own words, a majority reported a single ethnic origin. However, some described their ethnicity from various perspectives, for example, "Canadian," "Catholic," "Islamic," "Christian," "Diverse," "Caucasian Black," "mixed Norwegian, English and Native American," "Spanish, Chinese and American" and "mixed nationalities."

In the literature, ethnicity is often defined by self-perceived ethnic identity,

ancestral origin or both. The terms "race" and "ethnicity" are frequently used interchangeably in the classification of race/ethnicity although they are not synonymous. Race mainly refers to differences of biology, and ethnicity to differences of culture and geographic origin (Caldwell and Popenoe 1995). In hospital administrative data, the United States has employed a single category of race/ethnicity that includes six groups: American Indian, Asian, Black, Hispanic, White and Unknown or Missing (Moy et al. 2005). The United Kingdom has used the categories White, Black, Caribbean, Black African, Black Other, Indian, Pakistani, Bangladeshi, Chinese and Other (National Statistics 2001). New Zealand has used New Zealand European, Maori, Samoan, Cook Island Maori, Tongan, Niuean, Chinese, Indian and Other (such as Dutch, Japanese, Tokelauan) (Statistics New Zealand 2002).

Statistics Canada defines ethnicity in the Census as

> the ethnic or cultural group(s) to which the respondent's ancestor belongs. An ancestor is someone from whom a person is descended, and is usually more distant than a grandparent. Ethnic origin pertains to the ancestral "roots" or background of the population and should not be confused with citizenship or nationality. (Statistics Canada 1998)

Even though the definition in the Census has not changed through the years, the classification of ethnicity has been updated several times. In the 1991 Census, 15 of the most frequent origins were listed under the question: "To which ethnic or cultural group(s) did this person's ancestors belong?" and respondents were asked to mark as many as were applicable (see Table 2). In addition, two blank spaces were provided for respondents to write other responses that might have been applicable. In the 1996 Census, four blank spaces were provided for respondents to write in their origins, and 24 categories of such origins were provided as illustrations. In addition, "Canadian" was included for the first time as one of the categories because it was the fifth most frequently reported origin in 1991. The 2001 Census provided four blank spaces for respondents to write in their origins and provided 25 categories, the first 21 of which were based on the frequency of single ethnic origin counts from the 1996 Census. The National Population Health Survey (Statistics Canada 2004b) and Canadian Community Health Survey (Statistics Canada 2003) collected ethnicity information on cultural/racial background using 13 categories and ethnic/cultural ancestry using 19 categories.

Validity of ethnicity information is also related to the process of collection. The information should be recorded based on self-report. However, hospital clerks or clinicians may hesitate to ask for information on ethnicity because they may feel that such questions are discriminatory and offensive to patients (Caldwell and Popenoe 1995; Moscou et al. 2003). This scenario could result in some staff's guessing a patient's

ethnicity from name or appearance, or copying the ethnicity from previous records without confirming or updating it. Nevertheless, several studies have shown that the agreement between self-report and administrative data is high for Asian, Black or African American and White race/ethnicity, and relatively low for American Indian and Hispanic race/ethnicity (Moscou et al. 2003; Gomez et al. 2005; Kressin et al. 2003; Boehmer et al. 2002; Swallen et al. 1997).

This study has limitations. Because the survey was conducted in one Canadian city (Calgary), generalizability of the study findings to other regions is unknown. However, we believe the rate of agreeing to record ethnicity in hospital charts is likely to be high in Canada, as nearly all respondents in the CCHS survey answer ethnicity questions. Our non-response rate was 45%, which may bias our findings. In the introduction to the telephone survey in the community, we stated that the survey was being conducted for research purposes. However, recording information on ethnicity in hospitals or clinics would have many purposes beyond research, such

TABLE 2. Survey question and classification of ethnicity in the Canadian Census, the National Population Health Survey (NPHS) and the Canadian Community Health Survey (CCHS)

	CENSUS 1991	CENSUS 1996	CENSUS 2001	NPHS/CCHS	
Question	"To which ethnic or cultural group(s) did this person's ancestors belong?"			"To which ethnic or cultural group(s) did your ancestors belong? (For example: French, Scottish, Chinese).	"People living in Canada come from many different cultural and racial backgrounds. Are/is you/he/she … ?"
Format	Respondents were required to choose one or more from the 15 categories provided and/or to write answers in two write-in spaces.	Respondents were required to write in their ethnic origins in four write-in spaces and not required to choose from the 24 ethnic categories in 1996 census and 25 categories in 2001 census. These categories were provided as examples for consideration only.		Respondents were required to provide an answer from the race/ethnic categories.	

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TABLE 2. Survey question and classification of ethnicity in the Canadian Census, the National Population Health Survey (NPHS) and the Canadian Community Health Survey (CCHS)

	CENSUS 1991	CENSUS 1996	CENSUS 2001	NPHS/CCHS
Ethnic categories provided	• French • English • German • Scottish • Italian • Irish • Ukrainian • Chinese • Dutch (Netherlands) • Jewish • Polish • Black • North American Indian • Métis • Inuit/Eskimo	• French • English • German • Scottish • Canadian • Italian • Irish • Chinese • Cree • Micmac • Métis • Inuit (Eskimo) • Ukrainian • Dutch • East Indian • Polish • Portuguese • Jewish • Haitian • Jamaican • Vietnamese • Lebanese • Chilean • Somali	• Canadian • French • English • Chinese • Italian • German • Scottish • Irish • Cree • Micmac • Métis • Inuit (Eskimo) • East Indian • Ukrainian • Dutch • Polish • Portuguese • Filipino • Jewish • Greek • Jamaican • Vietnamese • Lebanese • Chilean • Somali	• Canadian • French • English • German • Scottish • Irish • Italian • Ukrainian • Dutch (Netherlands) • Chinese • Jewish • Polish • Portuguese • South Asian (e.g. East Indian, Pakistani, Punjabi, Sri Lankan), • Black • North American Indian • Métis • Inuit/Eskimo • Other – Specify • White • Chinese • South Asian (e.g. East Indian, Pakistani, Sri Lankan, etc.) • Black • Filipino • Latin American • Southeast Asian (e.g., Cambodian, Indonesian, Laotian, Vietnamese, etc.) • Arab • West Asian (e.g., Afghan, Iranian, etc.) • Japanese • Korean • Aboriginal Peoples of North America (North American Indian, Métis, Inuit/Eskimo) • Other – Specify

as administration, healthcare quality improvement and provision of culturally sensitive services. It is possible that respondents would have viewed the collection of information on ethnicity even more favourably had they been explicitly informed of such potential uses of ethnicity data. Future research, perhaps using qualitative methods, would be required to clarify respondents' perspectives on these nuances.

We hope that this simple study will encourage hospitals, health regions, the Canadian Institute for Health Information and the general public to engage in dialogue regarding the feasibility and ethics of beginning to collect ethnicity data at an individual level. The collection of such information has considerable potential to enhance our understanding of disparities in health and health system access and quality, so that interventions can be designed and implemented to contribute to the health of ethnic minority populations. A consistent format of gathering race/ethnicity information should be considered to achieve comparability among Canadian databases.

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